

Finding It on the Internet: Health Access for Elders

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Key project participants:

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Andrea Drury, MLS (RareHeron Web Design), Information Architect
Kayo Parsons-Korn (RareHeron Web Design), Designer
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Project statement

More elders are using the Internet all the time. Looking for health information is one of the most common activities on the Internet. This project was a result of these two trends. The purpose was to develop an easy-to-use web site with quality health information for elders, including links to local and national resources.

Visit The Prepared Caregiver at <http://www.ohsu.edu/healthyaging/caregiving>

Based on interviews with Oregon Health & Science University (OHSU) School of Nursing faculty and on suggestions from Marna Flaherty-Robb, the project's original liaison person with the School and the Center for Healthy Aging, the content of the site was narrowed to caregiving for elders. It was critical to put boundaries on the project, and with caregiving still a large subject area the focus was further defined as information useful to potential and new caregivers for elders. We assumed that the primary users of the site would be spouses or adult children of elders needing care.

Further content definition came from our decision to have the site concentrate on information for action rather than general knowledge. We included information about where to get help and specific guidelines. We also decided to incorporate psycho-social as well as bio-physical information.

We knew that the language used on the site had to be suitable for the audience and must avoid health care jargon. The reading level had to be no higher than eighth grade. At the same time, we wanted to avoid any sense of talking down to people.

Basic technical assumptions defined for the site included:

- pages that would load quickly even with a slow connection
- access for both PCs and Macs
- age appropriate fonts and font sizes
- age appropriate use of color and color contrast
- meeting Federal accessibility guidelines (Section 508)

Focus groups

Site development depended in part on usability information elicited from elders during focus group sessions. Information from the focus groups was also used to meet the secondary goal of the project which was to research the overlap between generally accepted best practice for elders' usability and usability requirements evoked from elders themselves.

Focus groups were scheduled for completion by early November 2002. The groups were actually held between the end of October 2002 and mid-January 2003. The OHSU Internal Review Board (IRB) had to approve the study because human subjects were involved. Unfortunately, their approval process took months to complete. Several things contributed to the delay. A team member deferred getting IRB training, forms were lost several times, and the approved version included inappropriate IRB standard language (like "patients" instead of "participants"). This necessitated a revision. The IRB process was finally complete in mid-October 2002. After that focus group participants could be recruited and grant money could be spent.

Criteria for focus group participation included:

- age 55 or more
- able to speak, read and write English
- have personally used the Internet to find information on web sites

We considered it desirable to have a range of educational levels, similar numbers of men and women overall, and an ethnic mix among participants. Focus group size was set at six people.

Separate groups for men and women were considered. Researching this question showed nothing conclusive. I found that it's sometimes advisable to separate genders, with no criteria given other than saying it could create better group dynamics and more sharing, and would avoid the "peacock effect" (showing off, often at length). I decided to use mixed groups since the topic was not gender specific and was non-threatening. This made scheduling much easier.

Another concern was whether to have spouses in the same group. One person may tend to defer to the other, or one person might speak for both. For practical reasons -- filling the groups and ease of scheduling -- I decided to have them together. As facilitator I was prepared to deal with any issues, but they did not arise.

The original plan was to recruit participants for two groups at the North Portland branch of Multnomah County Library, a branch with a computer lab. It seemed a likely place to find elders who were relatively new to the Internet. Only one participant was recruited in this way. The first group was held at the library, but most of the participants came from my own network of contacts.

The second focus group was at an assisted living facility, Providence ElderCare at Glendeever. I worked with Holly Nelson, a social worker, to get participants and to schedule (and reschedule) the meeting. Nine people signed up for the group and eight attended. Due to some cognitive impairments not all participants met the requirement for searching the Web. Some had confused doing email with web site searching. Another had used the Web, but didn't remember he had. Holly's help during the group was valuable in helping people understand the questions and see the relevance to their experience.

Influenza and the holidays delayed the focus group at Calaroga Terrace, a retirement home. I worked with the activities coordinator to recruit people and six attended the session in January.

The last group was held at OHSU. I recruited participants from my network, and they in turn recruited others. Six attended the session.

Each focus group participant received a \$25 Fred Meyer gift certificate as a token of appreciation for their time. This was very well received and made it easier to recruit.

Overall focus group demographics were:

- age range from 56 to 85
- all had English as their first language
- 13 women and 12 men
- 8 completed high school; 6 completed college; 11 had postgraduate or a professional degree
- 23 Caucasian; 2 Alaskan natives
- 20 retired; 5 not retired
- 4 new Internet users; 6 casual users; 13 experienced users; 2 non-users

When asked if there was any physical or mental situation which might affect their use of the Internet, participants noted:

- nothing (20)
- yes (4): ADD; mouse difficulty; vision and mouse; vision (can't see keys)
- no answer (1)

Focus group questions were developed and tested to make sure they made sense and would elicit the type of response expected. Since I wanted peoples' opinions and preferences I recognized that the information would be limited by what participants could consciously articulate.

Focus group results agreed with what experts say is important for elders' usability. One finding which was a bit different was the importance some focus group participants placed on a metaphor for the site. The metaphor of a trusted, knowledgeable friend

(like “my cousin who’s a nurse”) was suggested. This informed our site design and writing style. We also included photographs of contributors to the site to help users get a sense of the people involved.

Site content

There were issues with content for the site. The expectation was that OHSU nursing faculty would provide original content suitable for web publication, written at the right level for the intended audience. There was a mismatch of expectations.

By early September 2002 it was clear that our liaison with the nursing faculty appeared to have forgotten her role was to get content. A new timeline was developed with her; by early November nothing was done. A new liaison, Susan Butterworth, was found. Eventually we began to get content at the end of January 2003 and by the end of March we had everything we could expect to get.

Content problems included:

- late content, thus delaying site development
- less content than expected with fewer topic areas and less than needed in the areas we did get
- content in essay form rather than in a Web publication format
- unsuitable language level (from the nurse perspective it was in lay language but it was still very academic)

As a result, site development was significantly delayed. The design team, Andrea Drury and Kayo Parsons-Korn from RareHeron and I, could not begin realistic work on navigation without knowing what the content would be. In January we started an iterative process based on our best guess of content areas, information from focus group usability discussions and generally accepted design principles.

Once we began to receive content Andrea and I organized and rewrote all the material. This was a potential problem because some of the nurses had asked for assurance that their material would not be edited in any way without their permission. Since it was clear a lot of editing was needed, we said that instead they could have the opportunity to review the site and ask to have their content withdrawn. Fortunately, no one requested this.

Andrea and I identified important content areas that were missing and did research to fill in the gaps. As a result, not all the material on the site is from OHSU nursing faculty. We also added to the nurses’ list of sites to which to link.

Even with the compressed time frame for site development, we met our goal of May 1 for the draft site development. The last month of the project was spent testing and revising the site.

Usability testing

Elders were recruited to do usability testing on the site. I developed a script to use so everyone would have the same expectations about testing. Participants were recruited from OASIS and the Elsie Stuhr Center (two senior centers) and through personal networks. Usability tests were done at the OASIS computer lab and at peoples' homes. Each tester received a \$25 Fred Meyer gift certificate.

The purpose of the tests was to find out whether users could easily navigate the site to find requested information within a reasonable number of clicks. We looked for obstacles that prevented them from easy use of the site, and for things that caused confusion.

Usability testers were divided into groups with three to four testers in each group:

Eleven questions were developed that required testers to use different parts of the site. Questions were asked aloud, and testers were watched to see how easily they found the information. Comments people made as they navigated the site were noted.

The number of "clicks to find" were counted. Given the demographic being tested, number of clicks was thought to be more meaningful than the amount of time spent answering the question. The testers often read everything on the screen, which made them successful at finding information. It did slow things down and would have made "time to find" not very meaningful as a measure. It was clear that the testers felt finding information and learning was more important than moving quickly through the site.

After the usability test was done, testers filled out a web site rating sheet. It included a modified Lickert scale which asked them to circle the number that most closely corresponded to how they felt about The Prepared Caregiver site. For example:

Simple	3	2	1	0	1	2	3	Complex
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Friendly	3	2	1	0	1	2	3	Unfriendly
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Another section asked testers to indicate their level of agreement with statements about the site, for example:

The information I wanted was easy to find.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

It was physically easy to read the information on this web site

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

I found it easy to know where I was on this site.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

Based on what I observed during the usability test and on the rating sheet, I interviewed each tester to clarify what they meant and make sure all the problems, suggestions for improvement, and aspects they liked were captured.

The first few tests pointed out several areas that were confusing; changes were made immediately. Subsequent tests showed that the changes fixed the problems.

In addition to the usability test measures, the site also had to comply with federal accessibility guidelines. The Prepared Caregiver meets Section 508 guidelines and it meets Bobby guidelines for usability.

We also wanted the site to load quickly even with a slow modem connection. About half the tests were done in peoples' homes using a modem. There was never an issue with load speed.

Frank Spillers and Daniel Loewus-Deitch from Experience Dynamics did the expert usability review. Their report made a number of useful suggestions, many of which were incorporated in the site design. Due to the short time we had to develop the site some recommendations have been turned over to its host, OHSU's Center for Healthy

Aging, for future refinements. Examples of these include developing a site search feature and the ability to ask questions of the nursing faculty contributors.

Project evaluation

The project was completed on time and within budget. The site did not get loaded at the Center for Healthy Aging until several months after completion of the project, but it was ready for loading at project end.

- The site met usability test requirements.
- The site complies with Section 508.
- The site loads quickly with a modem connection.
- Testers liked the site and said they would use it and would recommend it to their friends. Several said they wished they had had a site like this much earlier.

Useful lessons

Focus groups:

- Focus groups take longer to set up than expected. It is harder to recruit people than you might expect. Double the time and effort you think it will take to organize focus groups.
- It is helpful to hold focus groups with older people in their own environment so they do not have to travel.
- Be flexible with groups of older people. You may need to adjust focus group questions to help clarify what you're after and to adjust to their experience.
- Be realistic about focus group criteria. Use only those that are essential. Each requirement for participation adds recruitment difficulty.

IRB process:

- Allow triple the time you think necessary for research requests to clear an Internal Review Board (IRB).
- Assume that things may get lost during an IRB process and do whatever you can to prevent this, including personally taking papers for signatures rather than mailing them. Make opportunities to visit the IRB staff so they see the person behind the paperwork. Pay close attention throughout the process.

Content:

- It is hard for professional people and academics to recognize when their language choice is free of jargon and easily intelligible to a lay person.
- When relying on others for content, triple the amount of time you expect it to take to receive material. Be prepared to do significant rewriting and editing, and to do research for additional information.

Usability testing:

- Get an expert to perform a heuristic evaluation of the site. It is a useful external check on usability. The evaluation is most helpful when the site is close to done yet enough time remains to make changes.
- Do some usability tests on peoples' personal computers. Screen size, type of equipment, and kind of connection all make a difference.

Project management:

- Recognize that people may not follow through with what they promise. Start reminding people as soon as they miss one deadline. Be persistent.
- If a team member is clearly not doing her part, find another person who can step in sooner rather than later.
- Build in a lot of time for unexpected delays.
- Make sure all the project participants have a shared set of expectations about the project and their role in it.
- Get these shared expectations written as agreements. Do not assume that having roles and responsibilities written in the project proposal will be sufficient.